

September 10, 2013

Margo Lachowicz
Access Health CT/Connecticut Health Insurance Exchange
By email: Margo.Lachowicz@ct.gov

Dear Ms. Lachowicz:

Thank you for the opportunity to comment on Connecticut's All-Payer Claims Database (APCD) Draft Policies and Procedures and Data Submission Guide. We are very enthusiastic about the potential of an APCD in our state to improve health care planning, control costs, improve the quality of care, and reduce health disparities. We offer these comments to expand on the draft policies and maximize the APCD's impact in reforming and improving our state's health care system. Our comments are derived from our report, [The Power of Data: Consumer Involvement and Accountability for Connecticut's All Payer Claims Database.](#)

We urge the development of a transparent, standardized process for access to data. We urge you to use a transparent process, including public input, for prioritizing data access and to create an independent group of experts and consumers to review applications. Any member of the group with even the perception of a conflicting interest should not only recuse themselves from voting, but should not be present for discussions about the conflicted application. The decisions of the data access group should not be subject to override by health insurance exchange staff. We also urge you to create an independent process, outside the exchange, for appeals of data access decisions. We recommended in our report, and echo here, that the health insurance exchange's applications for data access should be treated by the same rules and processes as other requests, without specific advantage. We strongly urge you to follow the lead of Massachusetts's APCD and post all applications for access to data that is not publicly available online, including the requesting institution and the purpose of the request, allowing public comment on all applications before approval. We also urge the development of a robust system to audit data use and significant penalties for breaches or disclosures to unauthorized parties, reverse engineering to re-identify data, or for any other unauthorized purposes.

We also recommend that commercial and marketing uses for the data be excluded in your policies. We understand that financial sustainability of the APCD is a concern, but public support is critical to the integrity and future of the APCD. We also urge a broad definition of commercial and marketing uses. For example, in an earlier Cabinet meeting an example use case was described in which a nonprofit advocacy organization for people with a specific disease would be able to get access to the data to invite people who may suffer from the disease or are at risk for it, to join the organization. Concerns were raised about privacy, uninvited invitations and access to the data or subsequent marketing by funders of the nonprofit possibly including pharmaceutical or device manufacturers.

We also urge you to develop a robust privacy and confidentiality policy, particularly as your long term goal is to integrate the APCD with clinical databases. Your draft relies heavily on HIPAA compliance. It is critical to go beyond minimum legal requirements to ensure people feel secure that their most sensitive health information is protected and will only be used to their and their families' benefit.

Thank you again for your thoughtful policy development and the opportunity to comment. We are happy to discuss these issues with you at your convenience.

Sincerely,

Jean Rexford

CT Center for Patient Safety
www.ctcps.org

Ellen Andrews, PhD

CT Health Policy Project
www.cthealthpolicy.org